

Governor's Commission on Mental Retardation

**The Road Ahead: Trends in
Mental Retardation Services at the
Beginning of the 21st Century**

A Staff Report

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Mental Retardation Services at the
Beginning of the 21st Century**

The Commonwealth of Massachusetts

GOVERNOR'S COMMISSION ON MENTAL RETARDATION

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Introduction

“...we have learned to create the small exceptions that can change the lives of hundreds. But we have not learned how to make exceptions to the rule that will enhance the lives of millions.”

—Lisbeth Schorr (1997), Common Purpose: Strengthening Families and Neighborhoods to Rebuild America

The last quarter century has witnessed profound, even lifesaving reform to services for persons with mental retardation. Care has vastly improved. Access to community living, education and employment opportunities, and health care are now the norm. At the same time, more people are being served; the DMR budget has never been greater; federal reimbursements for care are in the hundreds of millions. However, instead of coming to the close of a “revolution,” in many ways the work has just begun. Our focus on supporting lives richly lived still eludes us. Throughout the Commonwealth there are pockets of excellence where high quality services support high quality lives, yet these situations remain the exception rather than the rule.

The Governor’s Commission on Mental Retardation is charged with “examining the quality and effectiveness of the Commonwealth’s program of services designed to address the wide variety of needs of people with mental retardation.” To that end, the Commission undertook a series of activities to explore the critical issues that will shape our system of supports as the 21st century unfolds. These activities included:

- An extensive literature review;
- Telephone interviews with nationally renowned experts in the disability field;
- A public forum that consisted of five Massachusetts experts in the fields of family support, self-determination, housing, workforce development, and health care presenting their vision of a positive future for individuals with mental retardation and their families.

The identification of new strategies to overcome obstacles and develop new patterns of support is essential to program decision-makers and advocates as they continue to reflect on current systems. The purpose of this report is to examine several of the challenges that must be addressed in order to make high quality services supporting high quality lives the rule rather than the exception.

Family Directed Supports and the Challenge of Self-Determination

“There will be widespread acceptance of the notion that individuals can move themselves to great heights.” —Gunnar Dybwad

As the 21st century begins, it is universally recognized that raising a child with a disability can be stressful, even isolating. However, thirty years ago keeping one’s child “at home” was an inevitably lonely and often overwhelming task. Although small pockets of respite services were available earlier, it was not until the 1980s that families—not facilities—were recognized as the primary caregivers for persons with mental retardation. With this recognition, direct supports to the family slowly emerged. State agencies were often interested in expanding such efforts. Their motivation was hampered, however, by the absence of federal reimbursement for these types of services. It was not until the development of the federal Home and Community Based Services Waiver in 1981 that such family support programs expanded significantly.

National spending on family support grew from 1.6% of all MR/DD spending in 1992 to 2.3% of spending in 1996. Massachusetts is one of the top ten states in per capita spending for family support, with over 7.5% of the DMR budget allocated to this service.

The primary goal of family support is to provide families with a choice of services that will help them stay together. Although originally conceived as “respite” in which persons with mental retardation would leave the family home for a period of time, family support now offers many options. Families can use their allocations for respite care, but they can also purchase such things as services from an education advocate for assistance with IEP design and implementation, specialty clothes and equipment, a home computer or even a family vacation. Funding mechanisms used to purchase needed services include vouchers, reimbursement with receipts, and, in some states, direct cash payment. Family support funds can also go directly to a provider who in turn offers supports to the family. Watchwords for successful family support are family and community, choice and control, flexibility and responsiveness. Family support should also build on existing natural and community supports and maximize the use of generic resources.

These flexible supports are a boon to families with children who have developmental disabilities as well as families who have their adult children living at home with them. Families appreciate the flexibility of this approach but still express concern about the size of the stipend. Indeed, these stipends can be quite small, often only \$100 per month. Ensuring that such payments are adequate yet also equitable to other families is a systemic issue that has yet to be addressed. However, inadequate resources for families is just one of the major barriers to successful family support.

Another pressing issue that parents continue to face is the lack of viable after-school alternatives. At the Governor's Commission's recent forum on the future of supports, one parent expressed her frustration. "I'm not looking for something for free—but you can't buy what doesn't exist." Many families have two parents working outside the home. This scenario coupled with the release of secondary school students early in the afternoon leaves parents searching for appropriate after-school supports. When available, many after-school programs are geared towards younger children and may not be of the same high quality as school programs. As one mother of two teenagers with mental retardation noted, "(Our 16-year-old son) needs supervision, and he needs something to do that's enriching and fulfilling." Further, these programs seldom build upon the job training skills that are acquired during the school day. "We need some pre-vocational training...which the school is happy to provide, but only if it's before 2:30."

Other concerns have been raised regarding those families who are supporting children and adults with the most pervasive needs. This population accounts for less than 3% of the Massachusetts DMR system. These families need resources to be available particularly during times of crisis. Beverly Beyette, a staff writer at the Los Angeles Times, noted in a recent article that these families could be easily overwhelmed when their regular supports (nursing, direct care) are unavailable. Some states provide resources for emergency care. For example in California, a person can receive a short-term nursing home placement to give parents a much needed break. Delaware has no such organized provision. One family, who was nearly at the breaking point, brought their son to a hospital emergency room and left him there. These parents were subsequently charged with child abandonment. Families in similar circumstances have

become enraged that such measures were taken. Beyette writes: “While families who care for incapacitated and fragile loved ones do not condone what the couple did, most of them understand it. They see the incident not only as a cry for help but as a sign of overwhelming crisis in nursing care and the lack of government support for families struggling to keep disabled loved ones home and out of institutions.” In Massachusetts, children under the age of 22 who have significant medical conditions can usually receive respite through the four pediatric nursing homes in the Commonwealth. For adults, the focus is on maintaining a pool of workers who can go into the home and work extra hours when needed. For families of those with fewer medical needs there are out of home respite centers that provide nursing supervision (as opposed to nursing care).

There is widespread acknowledgement that families and individuals coming out of the education system have vastly different expectations of state-funded assistance. Those who are now entering the adult system are often **experienced self-advocates** who may have already made a significant impact on their own educational experiences.

Congregate care (even in a small setting) is less appealing to a young adult who has spent his or her entire life with family, and other types of **living arrangements** are often sought. Many of these individuals have already had paid work experience and expect that to continue with **jobs** of their own. Even more significant are the attitudinal changes. Many parents and young adults assume that opportunities to control resources and make choices that work for them will be available. Similar to the parent advocacy movement that demanded change in the state run institutions, so, too, do families and individuals want to make a significant impact on the entire system. Instead of only wanting government to increase and improve their services, the clarion call now is to provide funding and resource information and then let the family or individual maintain control. Tom Nerney, Co-Director of the Robert Wood Johnson program on Self-Determination for Persons with Developmental Disabilities, notes that many parents of children with disabilities do not want to join “the system.” He suggests that “self-advocates and parent leaders will join together and create a new political animal.”

Just as parents (vs. professionals) want to control their younger children's destinies, many youth and adults who have mental retardation also want ample choice and control in their own lives. This quest for family and individual control is often described as *self-determination*. A movement fueled by both families and self-advocates, self-determination is a way for an individual, with the support of his/her family, friends, advocates, and service coordinator, to gain control over the selection of services and who will provide them. Self-determination involves a true shift in power and changes the traditional decision-making roles of state government, agencies, individuals and families. While the concept is not new, few persons receiving services actually participate in a self-determination process. However, both national and state leaders predict that this opportunity will only increase. In a recent interview, Colleen Wieck, Executive Director of the Minnesota Governor's Council on Developmental Disabilities, notes that "The field of developmental disabilities is on the threshold of a promising new era in which individuals with disabilities will be able to exercise greater control over their destinies. The method of securing financing will be the key to ensuring success in the new century. Monies will be transferred and controlled by individuals themselves. Consumer direction will be the norm...."

Self-determination: Maximizing choice

Steven has been receiving supports funded by DMR for many years. He had been living in a traditional "program" for over ten years without much choice regarding his living situation. In part, this was because he had a reputation for having "severe" behaviors. Using the self-determination process, Steven and his service coordinator explored other living options. Steven was introduced to a married couple interested in shared living with a person with a disability. The threesome spent five months getting to know each other and, in December of 1998, they began living together. With the couple's support, Steven has accomplished many of his goals. He is able to do things he enjoys, such as tend a garden, help maintain the house, learn to cook, and entertain friends.

As access to individually planned and provided services has grown, the system of mental retardation services has been challenged. Bob Gettings, Executive Director of the National Association of Developmental Disabilities Directors, suggests "The principal challenge is not to demonstrate the validity of the self-determination principle, but rather to make the structural changes in the service system policies and practices that will permit self-determination to be

implemented on a system-wide basis.” The Robert Wood Johnson Foundation, the largest philanthropy devoted to health care, has spearheaded this effort by granting states small pots of money to do systems change work. One example in Massachusetts is the development of family governing boards that have been set up so that families control the allocation of resources for their community including family support, day services, and transportation.

Some see the movement towards self-determination as the natural successor to the parent advocacy movement. Yet, as the movement towards self-determination expands, there is no evidence that the parent movement is declining. Indeed because the goals of these two groups are so similar, both movements appear to be strengthening each other. Much work needs to be done in order for family and individual supports to come to the center stage of service offerings. Families and individuals need to unite around this issue to ensure that their voices are heard, and state leaders and policy makers need to evaluate the quality and effectiveness of such supports to ensure that expansion will be equitable, effective, and of high quality.

From Community Presence to Community Inclusion—An Unfinished Task

“It is not time to declare victory and leave the field. Acceptance of the importance of inclusion...community presence, participation, choice, and respect are by no means unanimously endorsed or legitimized in practice.” —Valerie Bradley, John Ashbaugh, Bruce Blaney (1994), Creating Individual Supports for People with Developmental Disabilities

When thinking about how to best support individuals with mental retardation, it is important to consider not only the formal support system of disability services, but also informal systems of support such as relationships, communities, and societal membership (Racino, 1994). Service systems can facilitate relationships, encourage connections, and even help to develop friendships, but these ties cannot be sustained without the ongoing support and commitment of community members. Describing where a person lives or works cannot adequately capture the degree of one's integration within a community. There is general consensus that people with disabilities not only need to be in the community, they need to be *part* of the community. Unfortunately, social isolation is common. Research has consistently shown that for the most part, people with mental retardation do not maintain many friendships (Amado, 1993; Abery & Fahnstock, 1994; Reidy, 1993).

Much work has been done to identify ways in which individuals can better connect with their communities. One idea that has been implemented is the concept of **circles of support**. These circles include friends, family members, co-workers, neighbors, and in some cases service providers. An important component of these circles is that the majority of individuals are not paid to participate. Circle members are present because they want to support the individual in creating meaningful community experiences. The circle members help to develop a vision with the individual and identify challenges and opportunities that the individual will encounter in pursuit of his or her dream (Ducharme, Beeman, DeMarasse, & Ludlum, 1994). Other methods include the identification and use of **bridge-builders or community connectors** for people with mental retardation (Reidy, 1993; Wilson & Coverdale, 1993; Amado, 1993). Well-connected community members

act as guides while facilitating new relationships and linking individuals with new experiences and opportunities. These efforts represent the ways that individuals, not programs, can facilitate integration (Reidy, 1993).

Some practitioners believe that paid services will never lead to true community membership. Despite paid assistance provided by the state, people's lives are incomplete. "People are often enveloped in a cocoon of services that disrupts their personal connections and limits their opportunities for relationships and to make contributions" (Racino, p. 178, 1994). Although they invariably play an important role in an individual's social network, residential staff are seen as having control functions and therefore cannot provide adequate social support (Abery et al., 1994). Because paid relationships lack interdependence, it is difficult to identify common beliefs, trust, and other factors that are inherent in typical friendships.

Because building bridges and supporting relationships are highly individualized, neither empirical research nor models for practical implementation can provide a blueprint for successful community integration. Friendships cannot be programmed, but advocates, families, and communities can be mindful of the importance of creating opportunities for these interactions.

The Changing Roles of Direct Support Workers

“As traditional roles and relationships have become more ambiguous, the notion of direct support workers as ‘allies’ of people with disabilities has gained acceptance.”

—William Ebenstein & Tecla Jaskulski (1996), Opportunities for Excellence: Supporting the Frontline Workforce

Because of the shift in state-funded mental retardation services from congregate care to individualized supports, the role of the direct support worker is evolving. As community residential and work settings become smaller, direct support workers have more autonomy and less oversight and guidance from supervisors (Hewitt & Larson, 1994; Middendorf, 1992). As the pendulum slowly swings towards natural, unpaid supports, an increasing number of individuals rely upon community resources for community membership. Yet, many people will continue to need support from paid staff. The role of direct support professionals is far from obsolete. In facilitating true inclusion, the roles of caregivers and skill builders evolve into community connectors (Amado, 1993). Research conducted by Amado revealed that human service staff believe that the biggest barrier to community inclusion is intolerance by community members. After staff implemented some community integration strategies, it was found that their own attitudes were the major barriers. While many people with mental retardation historically have had little experience making community connections, staff has also had minimal training in facilitating this process. As more people with mental retardation live and work in the community, facilitating community participation is a new role and one that must become a priority for direct support workers.

Direct service staff are often the primary supports for people with mental retardation, and yet they have the least amount of experience and training as compared with any other worker (Lakin, Larson, & Prouty, 1994). By the same token the job descriptions of direct service workers are broadening. Not only are they responsible for traditional activities, but their duties now include multi-dimensional tasks such as promoting community inclusion and providing health care support for an increasing number of individuals with mental retardation living in the community who also have complex medical needs.

In preparation for providing services, or changing or enhancing existing services, training for direct support providers is an essential factor in a comprehensive effort to establish, maintain, and improve service quality (Prouty, 1992). An especially important contributor to this effort is the Community Support Skill Standards Project (Taylor, Bradley, & Warren, 1996). This project identifies national skill standards for human service providers. An outgrowth of this project is the development of the National Skill Standards for Community Based Human Service Practitioners. These competency areas include: empowerment; communication; assessment; community and service networking; facilitation of services; community living and supports; education, training and self-development; advocacy; vocational, educational, and career support; crisis intervention; organizational participation; and documentation.

Many professionals in the field support the recognition of a credentialing system for direct support work. This voluntary system would acknowledge such achievements as longevity of service, the meeting of statewide certification requirements, completion of specialized disability-related coursework, demonstration of accepted human service practitioner competencies, and demonstration of consumer satisfaction with direct support services. Ebenstein (1995) identifies a variety of objectives that the implementation of a credentialing system could address. These include: reducing turnover; improving skills of direct support workers; improving direct support workers' access to educational opportunities; creating portable career pathways recognized across agencies; providing a rationale for incremental wage increases; increasing availability of skilled workers; improving the quality of supports provided by staff; and improving professional status and recognition of direct support workers.

In an informal survey, Marianne Taylor of the Human Services Research Institute (HSRI) investigated direct support workers' perceptions of career advancement at a state regional center. Many workers responded that if they wanted to advance in their careers, they would become certified as substance abuse counselors or as nursing assistants (CNAs). **Motivated and committed individuals are leaving direct support to pursue other caregiving roles that command higher wages and more respect because of an established credentialing system.**

It is clear that if a credentialing system is created in direct support, front-line workers will want to become credentialed. As Taylor aptly notes, “If you build it, they will come.”

Opportunities for career advancement are important to direct support staff and are believed to influence retention rates. In their study of recruitment and retention of front-line staff, Larson (et al., 1994) found that “stayers” were significantly more likely to feel that they could get a promotion than “leavers.” However, many direct support workers report that career opportunities are virtually non-existent. For those who do not want to move into management positions in the agency, there is no real career path. Silver and Taylor (1997) make the distinction between a career ladder and a career lattice. A ladder implies upward movement towards the management or administrative level, while a lattice encompasses the linear movement in direct support that can also lead to opportunities for growth and higher wages. For instance, the use of self-managed work teams would allow staff to work on the front lines while enjoying pay increases and different types of responsibility. This situation virtually eliminates the need for a hierarchical structure and empowers direct support staff.

The stability of the front-line workforce has been a consistent challenge for human service agencies. Both supervisors and direct support staff recognize that low retention is directly correlated with low wages. A growing body of research in the area of recruitment and retention supports this theory (Larson, Lakin & Bruininks, 1998; Lakin, et al., 1994; Mitchell & Braddock, 1994; Lakin & Bruininks, 1981). At the forum on the future of supports, Marianne Taylor noted that twenty percent of the direct support workforce is eligible for food stamps and other income maintenance programs, typifying “economic injustice at its worst.” According to supervisors, traditionally it was likely that employees would leave current positions to assume higher level ones in the agency. Now, workers move to other agencies or even other fields in their search for livable wages. Also, agencies supporting people with mental retardation compete for workers with other human service agencies as well as with the for-profit sector. As today’s strong economy allows job seekers to move around among agencies and even industries, it is difficult to sustain direct support workers.

Individuals with mental retardation and their families have come to expect safe and effective community supports. If the system fails in this obligation, the trust between families and service providers will be jeopardized, and these important ties will be frayed. One mother's statement signifies the potential danger of families' loss of faith in the service system. "I'm tired of sharing my dream with people who cannot help me fulfill it."

The quality of supports is directly dependent upon the front-line workforce. Recruitment and retention issues are only expected to intensify in the current economic climate. Creative efforts to address these problems must include a significant salary increase for front-line workers, expanded opportunities for career growth, and competency-based training programs that include a credentialing system. These changes would attract more qualified candidates and ensure that a competent workforce earns a commensurate wage. In offering services to families, policy-makers and practitioners make a commitment to provide quality. This quality will be compromised unless the field effectively addresses the recruitment, retention, and training issues that beset its workforce.

Housing: Opportunities and Challenges

“Adults with disabilities should be entitled to whatever personal assistance and supports they need to live fully in their own home and community with dignity, self-determination, and respect.” —Susan O’Connor & Julie Ann Racino (1990), Housing, Support, and Community

The ability to find affordable, quality housing has been a fundamental part of the American Dream. For individuals with disabilities, to find a place to call home can be an almost impossible task. These individuals too often lack the financial resources, technical assistance and support to make decent affordable housing a reality. In addition, Massachusetts is currently experiencing a true housing crisis for many of its residents, making it specifically challenging for people with disabilities to secure safe and affordable housing.

During the advent of community-based residential services, housing and support were one unit. Budgets were based on congregate care with as many as eight people living in a residence. These homes and other similar arrangements were operated by provider agencies that also served as landlords. In this way, the locus of control was with the provider agency. The primary method of securing resources was to combine funding for housing and services. This funding was not portable—if a person left a group home, he or she could lose the funding. This approach often left little room for choice and flexibility in designing housing arrangements. Advocates argued that this situation limited the involvement of persons with disabilities in creating innovative housing and support options and perpetuated a systemic dependence on service system housing.

In 1988, **the need to separate housing and support was clearly espoused** (Taylor, Racino, and Rothenberg, 1988). This strategy emphasized that services and supports should be brought to the individual in a living arrangement that he or she controls. Indeed in the 1990s such changes have been initiated with many providers making efforts to decrease their control and ownership of housing and subsequently increase the control and ownership on the part of people with disabilities. Supported living is a typical approach to this goal. This model recognizes that persons with disabilities must be given the opportunity to identify where and with whom they want to live. Lakin (1996) characterizes the best contemporary supported living programs for

persons with mental retardation as having the following features: (a) separating the selection and financing of the individuals' home, work and recreational settings from the services and supports they need to participate in those settings; (b) providing homes so that the individuals "control their own front door," and live with whom they choose, according to their chosen lifestyle; (c) bringing specialized behavioral, communication or health services to the setting in which the individuals live rather than making the individuals live where the services are located; (d) requiring service providers to be less intrusive and more respectful in how they bring services and supports into individuals' homes, job sites and other settings.

Forty-three states indicated that they were providing supported living services to 45,172 individuals in 1996, representing an increase from 21 states and 21,156 persons supported in 1992. The Massachusetts Department of Mental Retardation launched a supported living initiative in 1993, and in 1999, 3,339 consumers with mental retardation were residing in homes of their own with ancillary supports from the local DMR office.

Financing is a key issue in developing supported living arrangements. There are now several opportunities for people with mental retardation to obtain assistance through the public and private sectors to buy or lease a home of their own. They range from federal, state, and local initiatives and programs, to tax credit and community options developed by individual agencies, to the use of housing cooperatives. In some of these programs parents can help with the down payments. The use of trusts as a method of promoting home ownership for individuals with disabilities is growing in popularity. These range from family and private trusts to community land trusts that preserve land for affordable housing. Funding is also available through loans, grants or special programs such as those provided by the Office of Housing and Urban Development (HUD). Housing vouchers and certificates often provide assistance to low and moderate income renters to reduce their rental payments and enable individuals to live in decent homes. A housing subsidy is simply financial assistance given to an individual, organization or government entity for the purpose of housing or related costs. A frequently used voucher or certificate provided through the federal HUD program and administered by local housing authorities is "Section 8." People using these certificates are required to contribute a maximum of 30% of their adjusted monthly income to rent. HUD then pays the landlord the difference between what the renter pays and the fair market rent. This program is very much in demand,

but it is encumbered by long waiting lists in many communities. And often, once individuals with disabilities are lucky enough to obtain a Section 8 voucher, they are unable to find an apartment that costs less than the maximum allowable “rent ceiling.” In this case, individuals may be forced to give back assistance after months or even years of waiting.

Future directions in housing for people with disabilities can no longer be viewed as an issue to be solved by those involved in the disability field alone. “Housing is a community issue” (Laux, 1995), and building bridges between the housing and disability fields is the key to success. Given the importance of housing and homelessness as an issue in this country today, it is critical for people with disabilities to be part of accessing and planning for equal housing opportunities. CHAPA is one organization that has led advocacy efforts to gain housing resources for individuals who are homeless—a staggering number of whom have disabilities. In developing a housing policy for the next century, planners must recognize a distinction between housing, which includes the types of housing a person has access to and its legal dimensions through rental, private, and cooperative ownership; home, as a physical place with social, personal, and control dimensions; and household, which reflects decision-making across household members and the establishment of the household (O’Connor & Racino, 1990). These distinctions have critical dimensions that warrant review and study in developing a housing policy for the future.

A framework for developing housing strategies in the 21st century must address many issues. Housing for individuals with mental retardation and other disabilities must be **affordable**. Tax breaks and other financial savings plans will enable persons to better afford homes of their own. Education and enforcement of the Americans with Disabilities Act and Fair Housing Act must be in place to assure accessible and safe housing options. Funding for services must be **flexible** and **portable**. Consumers should be able to control the funding by choosing the services that best meet their needs, and opportunities should be available for **individuals to make real choices** in house, household, and home modification. Most importantly, service providers should explore ways to coordinate housing that is provided by housing organizations with support services provided by other organizations.

Access to Health Care: A Search for Equity and Quality

One important outcome of the numerous class action lawsuits regarding the conditions of the state run institutions was the dramatic improvement of health care services at those facilities. Concurrent with this improvement was the development of community-based residential settings. These “group homes” were designed for state school residents who could easily move to the community. These “early movers” had limited intellectual impairment and minimal health care needs. Few considerations of health care supports were necessary beyond the accessing of a primary care physician. By the same token, the champions of the widespread utilization of community living specifically rejected the “medical model” of care. Thus, the systematic development of healthcare supports for adults with mental retardation—including clinical standards of care—never emerged. Even in Massachusetts with its abundance of health care resources, consistent access to high quality adult health care has become a major challenge. Nor are these supports limited to physician care but include supports such as home-based care both for nursing and supervision, access to specialty care, and ancillary services such as occupational, physical, and speech-language therapy, assistive technology and durable medical equipment offered by providers who are knowledgeable about this population.

There has been a significant amount of research conducted that examines the types and amounts of health related services required by people with mental retardation and related conditions in the community. Among the support needs are a **system of organized primary health care** available to the individual on a routine and emerging basis (Kastner, Walsh, & Criscione, 1995; Master, 1987; McGee & Menolascino, 1989), **ongoing relationships with primary and specialty physicians** to provide continuity of care (Minihan & Dean, 1990), and **access to home health care and on-call and 24-hour nursing** (McGee & Menolascino, 1989; Pagel & Whiting, 1987; Taylor, Racino, Knoll, & Luffiyya, 1987).

Effective medical case management has also been noted as a potentially important but missing component of medical services for persons with mental retardation (Department of Health and Rehabilitation Services, 1988). Throughout her presentation at the forum on the future of supports, Mari-Lynn Drainoni, Director of Research and Program Evaluation at the Medicaid Working Group, emphasized the significance of healthcare coordination. There may be many

viable candidates who could assume this coordination role for an individual with mental retardation, including family members, the individual him or herself, a DMR nurse, or the long-term care provider. However, if this role is not clearly defined, there is a risk for fragmentation, overlap, or overall inadequacy in service delivery.

Persons with mental retardation have a much higher rate of at least annual health care visits than the general population, and family satisfaction with such visits is good (Hayden & De Paepe, 1991). However as A. Crocker suggests, persons with mental retardation remain “strangers” to the community-based health system. Health care providers may view such patients as expensive and time consuming to treat. Practitioners may have an inadequate knowledge base of the treatment issues for this population. In addition, the initial difficulties in communication regarding symptoms, medication, and lifestyle issues may lead to less than optimal assessment and treatment. Similarly, family and paid support workers may feel intimidated in their efforts to advocate on the patient’s behalf.

Our society is becoming progressively more aware that good health does not mean the absence of disease but **wellness**, and it is increasingly recognized that promotion of wellness is an important facet of primary care. The difficulties with making lifestyle changes in diet, exercise, and tobacco and alcohol use are essentially the same for persons with mental retardation as for the general population. This similarity has been further heightened as efforts have increased to assist adults with mental retardation to develop their own lifestyles based on their own preferences. Maintaining a healthy lifestyle within the context of increased choice can be especially difficult because making a lifestyle change can be viewed as “taking away a human right” rather than taking control of one’s own life. It is evident that the promotion of wellness is multi-dimensional. At the very least, health care professionals need to focus on it during medical appointments. Training for individuals, their families, and their support staff needs to be readily available.

Studies confirm the widespread perception that persons with mental retardation have more need for specialized medical services than the general population. However, while the frequency of such need may be higher than that of the general population, it has also been demonstrated that

the absolute utilization of the types and ranges of medical care and services is actually greater for other groups, including those with physical disabilities (Hayden & DePaepe, 1991). Studies indicate that only about 15% of persons with mental retardation are considered to be “high consumers” who need ongoing monitoring and frequent access to tertiary health care. In a Massachusetts study (Minihan & Dean, 1990), 61% of those with chronic medical problems were rated as being in stable health and required treatment by specialists less than once per year.

Although persons with mental retardation as a whole do not present with intensive health care needs, increasing numbers of those eligible for DMR services do have such needs. Supports such as home-based nursing care and 1:1 supervision and monitoring are issues confronting the state agencies as well as the hundreds of community-based providers of adult services. The two populations that present with such needs are those who are entering the system as young adults and have high levels of medical need and those who are currently receiving DMR supports and whose needs are rapidly increasing due to aging. Accessing adequate funding as well as finding qualified workers are two specific challenges. In conversations with providers, the desire to serve those with challenging needs is high, but the confidence that such needs can be met in the booming economy is much lower. For the state agencies (DMR as well as other EOHHS agencies) the challenge is how to stretch funds to meet the needs of those who already receive services and now need more, those entering the system who may have very intensive needs including 1:1 supervision and frequent nursing home-visits, and those requiring supports in the very near future due to the aging of their family caregivers.

Another facet of need is the increase in the population of those with significant on-going medical needs requiring the long-term use of sophisticated medical technology. Today, the support of people who are dependent on medical technology is possible in a variety of non-hospital settings, including schools, homes, and other venues for typical life activities. It is estimated that one out of a thousand children in Massachusetts is dependent on this type of technology which in years past would have only been seen in a hospital-type setting; one half of these children have cognitive impairments, one quarter of them are severely impaired. (No figures are available for the adult population.)

Unlike many segments of our society, virtually every person with mental retardation has health insurance, usually Medicaid, Medicare or both. Up to 70% of Massachusetts residents with MR/DD are dually eligible. This dual eligibility has important implications for access to services and also impacts the scope of managed care plans. Managed care enrollments are increasingly a part of the lives of persons with mental

Managed care systems generally integrate the financing and delivery of primary acute care (and much less often long-term care). There are many variations in managed care, but all include some degree of risk and potential financial benefit to a managing entity responsible for providing and/or securing needed services for a group of people within an established budget.

retardation. Considerable effort has gone into the impact analysis of managed care plans for those with special needs. Pulcini and Howard (1997) provide an example of one such consideration. They provide a framework for assessing the adequacy of such plans by suggesting that a particular model should be reviewed on three levels:

1. Access including location; compatibility (match of service and need); the degree to which services segregate or integrate individuals with disabilities; and penetration (the percentage of clients served in a particular area).
2. Comprehensiveness which examines the levels of care, scope, health promotion, health care coordination, and staff training.
3. Financing which considers revenue mixes, supplementary funding, and structure of capitation (including capitated risk for the provider).

The specialized health care needs of people with severe disabilities are increasingly recognized. Several providers, most notably Community Medical Associates (CMA), now part of Neighborhood Health Plan, have contracted with Medicaid to provide services to people who have intensive needs. CMA is a managed care provider that specializes in treating persons with severe disabilities. CMA is founded on the principle that intensive coordination and assessment by a person's primary care provider improves health and prevents costly "specialized" treatments. Each CMA patient is assigned to a nurse practitioner/physician team that provides total primary care and case management services in all settings including in-patient hospitalizations. Patient satisfaction with this model is remarkably high as is the National

Committee for Quality Assurance (NCQA). They report: “overall the comprehensiveness of the benefits available under the CMA program in conjunction with the significant efforts the provider makes to ensure the coordination of care across multiple settings makes this an exemplary program.”

While several “shining stars” have emerged in health care access and quality, there is ample evidence that such access to medical care and its related supports is inconsistent. Standards of clinical practice and related supports are desperately needed and should be achieved in partnership with the various human service agencies (most notably DMR and DMA/Medicaid). One model that these standards might be based on has been developed by the New England Standards and Indicator of Quality Care for Children with Special Health Care Needs (SERVE). Training among health care professionals regarding the needs of this population and those with other disabilities also needs to be increased. More needs to be done to provide resources, techniques, and individual consultation to promote wellness within this group. For those with intensive needs, services such as those provided by CMA must be readily available. As people with mental retardation and other developmental disabilities test and extend their abilities to live as independently as possible, families, advocates, and state agency staff must develop and implement strategies that sustain and improve access to health care service delivery for this population.

Conclusion

“Nationally, the highest standards of care are designed to promote individual supports and services, personal choices for consumers of services, use of community resources and support, capable of finding a balance between protection from harm and the pursuit of individual independence. The shift in services from a program base to an individualized supportive service base is a difficult transformation for any state system. To achieve these goals, DMR will continue to need adequate financial support from the state, the ‘green light’ to experiment with new models of services and supports, and courageous leadership at all levels.” —Marty Krauss (1995), Report to the Governor on the Quality of Care in Massachusetts

At this time, the Commonwealth has much to be proud of in the current provision of care and support to its citizens with mental retardation. There are many dedicated people who serve in professional, management, and direct support capacities. There has been a remarkable investment in the monitoring of the quality of care through the Department of Mental Retardation. Emphasis on individualized service provision dates back to the original consent decrees and the development of the first ISPs. By the same token, it is widely acknowledged that the “flagship” programs—programs that are successfully delivering high quality services—are far too few. Over the last six years, the Governor’s Commission on Mental Retardation has been persistent in its call for these exemplars of quality to be replicated throughout the “fleet” of service offerings. The challenge of the next decade is not determining in what direction we need to turn, but rather dedicating ourselves to making these aspirations a reality.

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